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ABSTRACT

This handbook is designed to help older persons and their families understand the concept of home care, the types of services available, and the agencies that provide them. It also provides consumers with guidance on how to evaluate the quality and cost of home care they or their loved ones may receive. These specific topics are discussed: (1) who benefits from home health care, including the advantages of home health care and who provides the care; (2) arrangements for home health services, including locating home health agencies; (3) services friends and community organizations can provide such as day care programs, telephone reassurance, friendly visitor programs, hospice, meals-on-wheels, respite care and transportation programs; (4) evaluating the quality of home care services, and (5) how to arrange a homebound person's environment. Definitions of 18 terms are provided, including chore services, pulse, social worker, and walker. Checklists for selecting a home health agency and home health agency service are included. A resource list of free publications from the American Association of Retired Persons is provided. National home care associations are listed. (ABL)

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A HANDBOOK ABOUT CARE IN THE HOME

INFORMATION ON HOME HEALTH SERVICES

A Publication
of Health Advocacy Services
Program Department

American Association
of Retired Persons

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A HANDBOOK ABOUT CARE IN THE HOME

INFORMATION ON HOME HEALTH SERVICES

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FOREWORD

The American Association of Retired Persons has launched a national campaign to reduce the skyrocketing costs that are weakening our health care system and to help people use the health care system more effectively. Among the goals of the campaign are to provide consumers with more information and to bring about more competition in the health care field by encouraging the development of alternatives to traditional methods of care.

One such alternative is home care. It can allow persons with debilitating or chronic health problems to remain in their homes rather than having to go to a nursing home.

Because of a great deal of interest among AARP members and others in investigating home care as a health care option, and because of their concern about a lack of consumer information on the subject, we have developed this Handbook. It is designed to help older persons and their families understand the concept of home care, the types of services available, and the agencies that provide them. Just as importantly, it provides consumers with guidance on how to evaluate the quality and cost of home care they or their loved ones may receive.

We are grateful to the representatives of the following national home care organizations who have provided comments, suggestions and continuing support as we have developed this Handbook:

- American Federation of Home Health Agencies
- American Home Health Service Suppliers Association
- American Hospital Association Division of Ambulatory and Home Care Services
- Home Health Services and Staffing Association
- National Association for Home Care
- National Home Caring Council
- National League of Nursing Council of Community Health Services

We hope this Handbook will help you make the right decisions and become better health care consumers.

Horace Deets
Executive Director

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INTRODUCTION

At a 1978 congressional hearing, the following story was told: An 86 year-old woman, partially blind and with no immediate family to care for her, felt obliged to agree when her friends and physician suggested she leave her home and move into an institution. Although she was ambulatory, able to dress and feed herself and clean her room, she did need assistance in reading medication labels and preparing meals. The cost for her to live in an institution at the time was $1,140 per month compared to an estimated cost of $325 per month if homemaker-home health aides had been provided.

The woman had to leave her home, her familiar community surroundings, most of her valued possessions, and neighborhood friends to move to an institution. As a result of moving, she was forced to adjust to a new lifestyle. With a daily visit to the home by a nurse or aide to help her with medications, and an arrangement with the Meals-on-Wheels program to deliver meals to her home, she could have remained independent and comfortable in her own familiar environment.*

Although home health care has gained in popularity since then, many people are still unaware of its availability. Many thousands could benefit if they knew about the kinds of home health services available, where to look for and how to arrange for them, and how to pay for and evaluate the care received.

Knowledge about home health care has become increasingly important in recent years. Since October 1983, Medicare's new Prospective Payment System for reimbursement to hospitals has encouraged hospitals to discharge patients sooner and treat more patients on an outpatient basis in order to cut hospital costs. As a result, there is a greater demand for home care services since many nursing home facilities are not sufficiently equipped to handle the increased need.

This Handbook provides information to help older persons and friends or relatives make informed decisions about home health care. A description is given of supportive services (Meals-on-Wheels, day care, etc.), which can be used alone or in combination with home health services to allow a person to remain within his or her home. As a planning manual, the Handbook can help individuals arrange for their own care or supply useful information for friends or relatives. And perhaps most importantly, it can help eliminate the fear and uncertainty that often accompany health problems by explaining realistic options in the community.

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*U.S. House of Representatives. *Home Care for the Elderly: The Need for a National Policy.* Hearing before the House Select Committee on Aging. 95th Congress, 2nd Session. February 22, 1978.

WHO BENEFITS FROM HOME HEALTH CARE?

Home health care* is care brought to the home to maintain or restore a person's health and well-being.

Home health care is often appropriate for older persons recovering from illnesses such as heart attacks, strokes, or accidents, i.e., acute care; those suffering from chronic conditions requiring long-term care such as diabetes and high blood pressure; or those suffering from terminal illnesses. For example, a stroke or incapacitating accident may hospitalize an individual temporarily after which he or she may simply require bed rest. The person may also need someone to help at home with chores, getting into and out of bed and bath, and with physical or speech therapy. Even if a relative or friend is available and can help, professional care such as part-time nursing or physical therapy or supportive services such as homemaker-home health aide services may still be needed.

*Home health care is also the term used by Medicare to denote specific home health services reimbursed by Medicare. In this text, home health care refers to the wide range of home health services available, not just those reimbursable under Medicare.

The Advantages of Home Health Care

Health care in the comfort and security of home gives an older person and his or her family and friends a sense of control and peace of mind. It also helps to reduce the strain that excessive hospital or nursing home bills can cause during a long-term illness or disability. Remaining at home also helps many older persons maintain social ties and involvement with the community, neighborhood, friends and family, and preserves their sense of independence and security.

If they are forced to enter a nursing home, many elderly leave personal possessions, hobbies, and social contacts behind, sometimes permanently. Home health care can help them avoid this problem. However, some older persons who have few friends or relatives, whose living conditions are poor, or who require highly skilled health care may be better served by placement in a nursing facility or another alternative living arrangement or care plan.

Home health care consists of a wide variety of services provided to older, disabled, and/or convalescent persons who do not need institutional care but require some assistance in meeting their health care needs. Its services fall into two general categories: skilled care and supportive services. Skilled care is given under the general direction of a physician and consists of health services provided by licensed professionals such as registered nurses and professional therapists. Supportive services are those provided as an adjunct to skilled care that enable a person to continue independent living within the home. Supportive services include assistance with personal needs (walking, bathing, dressing, etc.) and chore services (shopping, meal preparation, light housekeeping, etc.).

A variety of sponsoring agencies provide home health care services, usually under a physician's orders, as fre-

quently as necessary. Some agencies operate seven days a week, but most operate on a normal work week schedule. Most of them provide a range of services, which can include:

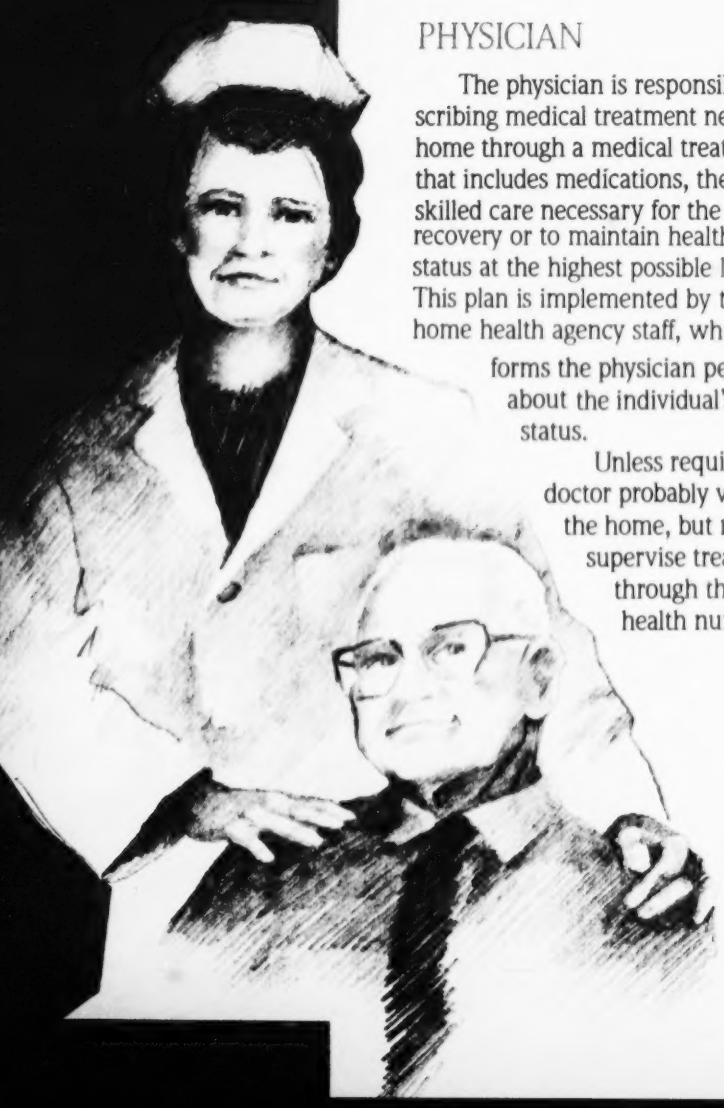
- nursing care
- physical therapy
- speech and hearing therapy
- occupational therapy
- homemaker-home health aide services
- nutrition counseling
- social services
- laboratory services
- dental care
- transportation services
- medical equipment and supplies

The health professionals involved in home health care delivery are:

PHYSICIAN

The physician is responsible for prescribing medical treatment needed at home through a medical treatment plan that includes medications, therapy, or skilled care necessary for the patient's recovery or to maintain health status at the highest possible level. This plan is implemented by the home health agency staff, which informs the physician periodically about the individual's health status.

Unless required, the doctor probably won't visit the home, but rather will supervise treatment through the home health nurse.



NURSE

A registered nurse employed by the home health agency visits the person at home to evaluate his or her condition and determine the type of nursing care required to carry out a physician's medical treatment plan. The nurse discusses this treatment plan with the individual, and, if appropriate and necessary, the family.

The nurse maintains contact with the physician and notifies him/her of any changes in the patient's medical condition. Home health agency nurses often instruct the patient and family (if appropriate) on basic home care techniques, such as changing sterile dressings and catheter care. Such guided instruction fosters an individual's self-control and independence.

PHYSICAL THERAPIST

Physical therapy is frequently needed by a patient who has lost some use of his or her limbs or muscles because of an illness or accident.

After reviewing the physician's medical diagnosis and treatment plan, a physical therapist visits the patient at home, as required by the care plan. The therapist prepares a treatment schedule and visits the patient on a routine basis until determining, after consultation with the physician, that therapy is no longer necessary or advisable.

The therapist routinely talks with the home health agency nurse and physician to discuss the patient's progress, and may also instruct the patient on basic exercises to complete between visits.

SPEECH, LANGUAGE AND HEARING PATHOLOGIST

A speech, language, and hearing pathologist may be recommended by a physician if the patient has suffered an illness or injury that has affected speaking or hearing ability and/or language skills. The pathologist helps the patient re-learn and practice language skills and continues therapy until the patient, pathologist, and physician decide it is no longer necessary.

OCCUPATIONAL THERAPIST

An occupational therapist may be needed by a patient who has suffered an illness or injury that has affected daily activities, movement, or perceptual abilities. The occupational therapist evaluates the patient's ability to dress, wash, walk, or perform other routine functions, and, when necessary, provides devices that add to the patient's comfort. Examples include:

- using larger buttons on clothes to facilitate dressing
- adding a board to the arm of a wheelchair to help support a patient's paralyzed arm
- providing a leg or ankle splint to aid in walking.

If a patient has suffered an illness resulting in paralysis in one part of the body, the therapist helps him or her learn how to dress and eat using the other hand. Daily living skills are practiced to help reduce the individual's dependence.

NUTRITIONIST

A nutritionist may be requested by the home health nurse when a patient needs help planning a special diet or restricted eating plan. For example, persons with diabetes, heart conditions, or high blood pressure must learn to eat fewer high fat foods, avoid sugar, and/or restrict salt intake. The nutritionist prepares menus that are appetizing to the patient, free of harmful food, and based upon the patient's food likes.

SOCIAL WORKER

If a patient is having difficulty adjusting to physical limitations of an illness or injury, the home health agency nurse may recommend a professional social worker to help the person and the family cope with the homebound situation.

The social worker evaluates the amount of support the family is able to provide the homebound relative. *Support* is defined as the amount of time, skill, or financial resources a family is able to give to a patient. If family members are able to help care for their relative, the social worker explains how they can make the patient more comfortable, recommends community services the patient may benefit from, identifies resource to support family caregivers, and helps the patient and caregiver obtain these services.

HOMEMAKER-HOME HEALTH AIDE

A homemaker-home health aide may be requested by the home health nurse when a person needs help with personal care because of impaired health or disability. Homemaker-home health aides receive training and orientation to provide a wide variety of personal services such as assistance with walking, bathing, or dressing, and chore services such as meal preparation, food shopping and light housekeeping. They may also administer oral medications under the supervision of the home health nurse and make reports to the home health nurse about the progress of the patient.

SPECIFIC PROFESSIONAL SERVICES

Instruction On Self-Care

Self-care instruction involves such home care techniques as insulin injections, ostomy care, post-mastectomy exercises, catheter care, etc. The nurse may also teach the patient how to perform many of the routine functions a nurse or nurse's aide provides for hospitalized patients, such as bathing or taking medication.

Wound Care and Dressing

The nurse routinely checks, treats, and applies new dressing to bandaged wounds, and may also teach the wound dressing procedure to the patient or family.

Catheterization

The nurse catheterizes patients who are unable to pass urine, and may also teach them how to care for an indwelling catheter.

Injections

Many medications must be given by injection. The nurse visits patients on a regular basis to give intravenous fluids, medications, or injections as prescribed. In some cases, such as allergy or insulin injections, the patient and/or family can be taught to administer injections.

Certain medications other than injections must be given under professional supervision because they are narcotic, or because the patient must be watched for side effects, or is unable to take medications without assistance.

Vital Signs and Blood Pressure

The nurse may routinely need to monitor a patient's blood pressure, temperature, or pulse.

Diabetes Treatment

This treatment requires a daily insulin injection. If the patient is able, the nurse provides instruction on self-injection and counsel on proper diet and exercise.

Physical Therapy

Massage, heat, and electrical treatments are combined with exercise programs to rehabilitate muscles.

Speech, Language and Hearing Pathology

Voice retraining is conducted after an illness or injury that affects speech. Other instruction teaches patients how to accept and compensate for a hearing loss.

Occupational Therapy

The patient is retrained in daily activities (i.e., dressing and feeding) that have become difficult from loss of mobility.

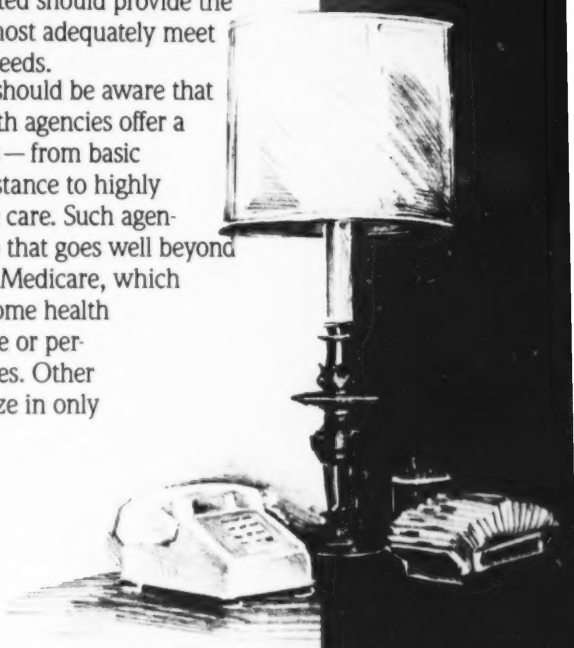
ARRANGEMENTS FOR HOME HEALTH SERVICES

Home health care is provided through various private agencies (profit and non-profit), hospitals (public and private), and public health departments.

Private agencies, whether non-profit or profit-making, are most commonly the providers of the kinds of services listed on the preceding pages. Profit-making status is not an indication that services are inadequate or overpriced. Good care may be obtained through agencies of any auspice.

Profit-making agencies sometimes fail to meet the tax status requirements mandated by a particular state for licensing. However, this failure doesn't indicate that the care they provide is any less adequate than provided by non-profit agencies, and no longer has any effect on their eligibility for Medicare certification or reimbursement. The agency selected should provide the services which most adequately meet the individual's needs.

Consumers should be aware that some home health agencies offer a range of services — from basic homemaker assistance to highly specialized acute care. Such agencies provide help that goes well beyond that financed by Medicare, which covers limited home health care but no chore or personal care services. Other agencies specialize in only a few services.



In many communities there is a lack of coordination between the various federal, state and local agencies providing services. Without a central comprehensive program handling everything from needs assessment to delivery of services, many elderly persons and their families must make trips to several agencies, each with a different application form, eligibility standard and assessment procedure. In addition, services that different agencies provide may overlap or, in some communities, certain services may be unavailable.

The key to an effective home health care system is the availability of a wide range of services and a system that allows for a selected number of services to be chosen and combined in individually designed programs. The absence of one key service may well mean that the effort to maintain an individual in the home will fail. Therefore, the consumer should try to arrange for a comprehensive and well-coordinated home care program.

The last section of this Handbook suggests ways to evaluate an agency's services and staff.

HOSPITAL-BASED HOME CARE SERVICES

Hospital administrators across the country have realized that many discharged patients aren't fully able to care for themselves at home, and that home health agencies can provide these patients with necessary nursing and therapeutic support. Hospital discharge planners may coordinate arrangements for home care. They can provide assistance in the selection of appropriate home care providers and ensure that transfer records are correct to facilitate a timely discharge. The discharge planner can help the patient order equipment such as hospital beds, wheelchairs or respiratory aids so that such equipment will be waiting at home upon discharge.

Some home care agencies will work with the discharge planner to conduct family training before patient discharge and provide a long-term written nursing plan.

Some hospitals have established their own home health care programs that serve as an outpatient extension for care received in the hospital. The care they provide is basically the same as that provided by private home health agencies.

A patient is not required or obligated to choose a hospital-based home health agency if additional treatment is needed upon discharge from the hospital. Selection of a home health agency should be based upon needs, individual preference, and availability.

PUBLIC HEALTH AGENCIES

Some local or county public health agencies provide home health care. If a person is homebound and interested in these services, he or she should contact the local public health department or welfare agency for specific information concerning available services, costs, and reimbursement.

LOCATING HOME HEALTH AGENCIES

Information about home health agencies can be obtained from many sources, including:

- local hospital discharge planners
- local or county public health and welfare departments
- social services departments
- Area Agency on Aging
- United Way (lists non-profit voluntary agencies)
- telephone directory
- Yellow Pages under "Home Health Services" or "Nurses"
- churches/synagogues
- adult day care centers
- medical or surgical centers
- nursing facilities (homes)
- Social Security Administration
- physicians

ESTABLISHING AN APPROPRIATE CARE PLAN

Contacting a physician is the first step in developing a care plan. The physician then evaluates the individual's medical condition and prescribes treatment needed in the home setting. A home health agency that suits the identified needs should then be selected and visited by arrangement with the agency's visting nurse who evaluates the individual's health needs and develops a nursing or therapy plan. In the event medical treatment is not required, a home care organization should still conduct a comprehensive assessment including a home visit.

The frequency of home visits from a nurse, homemaker-home health aide, or therapist will vary, such as once a day, or once a week, as determined by the plan of care. Depending on the condition, treatment may last from a few weeks to several months or on an indefinite basis. If the treatment extends over a long period of time, the physician should be consulted regularly to evaluate the patient's ongoing medical needs and determine if changes are needed in treatment or medication. The individual, physician and home health nurse can determine when or if health services in the home are no longer needed.

ELIGIBILITY FOR HOME HEALTH CARE BENEFITS

Most home health agencies provide home health services, including homemaker-home health aide services, to anyone who requests them. Expenses for skilled services required in the home are reimbursable through Medicare under specified conditions, Medicaid, and a growing number of private insurance plans. Some agencies that provide supportive services receive limited funding under Title III of the Older American's Act or under the Social Services Block Grant. These funds help provide homemaker-home health aide services, some of which are not covered by Medicare or Medicaid, to individuals who meet the state specified eligibility requirements. Interested individuals should check with the provider agency selected or their local social services agency to determine their eligibility.

MEDICARE REIMBURSEMENT

If a person is *confined to home* by an injury or illness needing medical treatment or therapy, and is entitled to receive Medicare, he or she may qualify for *part-time, skilled* health care services. Medicare reimburses costs of home health aides who perform functions analogous to those of hospital aides, such as help with bathing, eating, and dressing if the individual meets the defined eligibility criteria noted on the following page. Medicare, however, does *not* reimburse the costs of services furnished primarily to assist persons in meeting personal, family, and domestic needs such as general household services, meal preparation or shopping. Also, it rarely provides for long-term care of chronic conditions in the home.

Homemaker-home health aide services are essential supportive services which studies have indicated can prevent the need for institutionalization, especially for those suffering from chronic illness. The consumer should be aware that they generally will have to cover the costs of these services due to a lack of other financing.

Medicare consists of two types of insurance—Part A (Hospital Insurance) and Part B (Medical Insurance). Both parts cover home health care services and expenses. The types of services covered and the qualifications for coverage are the same for both Part A and Part B.

Covered Services

Home health services reimbursable by Medicare include:

- part-time or intermittent skilled nursing care
- physical therapy
- speech therapy
- occupational therapy

If any of the above services are required, the following services may also be available and reimbursable:

- part-time or intermittent home health aides
- medical social services under the direction of a physician
- medical supplies and equipment available from the agency.*

A person must meet all of the following requirements to receive Medicare home health coverage:

- A physician must certify the need to receive home health services for treatment of a medical condition. The physician must set up and periodically review a *plan of treatment* for these services.
- The care needed is *part-time or intermittent* skilled nursing care, physical therapy, or speech therapy. Present guidelines allow daily visits for a maximum of three weeks.
- The person must be confined to the home, but not necessarily bed-ridden. Individuals can remain eligible if they leave home infrequently, so long as such trips are short and for medical reasons.
- The home health agency providing the services must be a Medicare-certified agency.

If all the above conditions are met, Medicare pays the *reasonable* costs for an unlimited number of covered home health visits. *Reasonable costs* are fixed rates of reimbursement for services deemed necessary and restorative in value by Medicare personnel.

A home health *visit* is defined as each service a home health agency delivers to a person at home. For example, if a nurse comes to the home twice a day to administer shots, *two visits* have been made. If a speech pathologist helps the patient with a speech problem in the morning and a homemaker-home health aide arrives later in the day, *two visits* have been made.

The patient is charged only for services or costs that Medicare doesn't cover. The home health agency director can be questioned to determine as closely as possible how much of the bill the patient will be responsible for, and how much Medicare will pay. Because the agency is *certified* by Medicare, the patient does *not* have to send any bills to Medicare. The agency will submit the bills and claim forms for the patient.

The following services are *not* covered by Medicare under home health benefits:

- *full-time* nursing care at home
- drugs or biologicals
- meals delivered to the home
- homemaker or chore services that are unrelated to patient care
- custodial or personal care services.

The consumer should be aware that because the statutory language does not explicitly define "intermittent care," "skilled care," and "homebound," various regional intermediaries have had extensive leeway in interpreting the requirements. Therefore, the availability and coverage of services varies across the country.

MEDICAID ELIGIBILITY

Medicaid helps provide payments for medical care for eligible needy and low-income persons. Eligibility is based on monthly income limits and poverty requirements (limits on savings accounts, property value, and other assets). Federal, state and local funds finance the program which is run by state governments according to federal guidelines under Title XIX of the Social Security Act. Because each state is responsible for its particular Medicaid program, eligibility and coverage vary

*Effective January 1, 1990, beneficiaries will be able to receive care for up to 6 days/week for as long as needed (rather than the current four or less days/week—2-3 week limitation if care is needed five or more times/week). Those who need care 7 days a week will be covered for up to 38 consecutive days.

from state to state. In addition, certain states have obtained a waiver from the federal government under Section 2176 of the Omnibus Reconciliation Act of 1981 which allows states to offer home and community-based services to individuals who would otherwise be institutionalized.

If included in the state's Medicaid program, Medicaid will pay the medical expenses of an eligible person receiving home health care services, but not all agencies will accept Medicaid patients because the cost paid by Medicaid to the agency is often less than the actual cost of care or less than the amount the agency would receive from a private, full-paying patient. A patient eligible to receive Medicaid should first inquire if an agency will accept Medicaid patients. If it does, Medicaid may provide more services than Medicare, particularly in the area of personal care service.

PRIVATE INSURANCE COVERAGE

In the past, private insurance plans haven't included coverage for home health services, but many major health insurance firms have recently incorporated partial coverage for home health care into their policies. Some major medical policies also provide coverage for certain home health services. Private insurance companies should be contacted to determine if home health coverage is included in their policies. It should also be determined whether the home health agency that provides service accepts private insurance for home health care services. Consumers should evaluate policies carefully noting costs, limitations and restrictions.

VETERANS ADMINISTRATION COVERAGE

Several Veterans Administration hospitals across the country have established pilot programs to deliver home health care services. Most plans offered by the Veterans Administration provide coverage for health services in the home if they are needed because of a service-connected disability. A veteran confined to his or her home should contact the nearest Veterans Administration hospital to discuss eligibility. The health plan for military dependents (CHAMPUS) also provides coverage.

SERVICES FRIENDS AND COMMUNITY ORGANIZATIONS CAN PROVIDE

Many services, some of which are low cost or free, are available in some communities to assist persons confined to their homes, including:

■ **Day Care Programs** usually provide medical services as well as social and recreational programs. The people who benefit most from day care activities are those who live alone, or whose family and friends work during the day. Day care programs usually operate five days a week, 9 a.m. to 5 p.m., and are often sponsored by religious, fraternal, or neighborhood organizations, or a unit of a hospital or clinic.

The medical help available is usually limited to administering medicines or minor medical treatment supervised by a registered nurse. Occasionally, speech or hearing therapy, physical therapy, or occupational therapy is available, but participants are expected to be mobile.

The cost is usually about $10 to $30 per day, but some programs are free or operate on a sliding scale that adjusts payment to income. Community organizations frequently sponsor individuals who cannot afford to attend. Medicaid is probably the major source of payment for most people, and must approve each person's eligibility.

Home health care nurses may recommend participation in adult day care programs when a patient completes home care treatment and is physically able to leave the home.

■ **Telephone Reassurance** is a free service provided by church, civic or fraternal organizations and sometimes by home health agency volunteers. This service provides daily contact for persons who live alone, or who are alone during the day and worried about their health or safety. The client calls in every day at a predetermined time, or a volunteer will call the client. If a client doesn't call in, or if calls by a volunteer aren't answered, the neighbors or police are alerted to check on the client.

- **Friendly Visitor Program** is similar to the telephone reassurance program, except that someone visits the patient on a regular basis rather than simply calling on the telephone. The volunteer's visit is usually scheduled for a pre-determined, regular time, usually once or twice per week.
- **Hospice** represents a philosophy of care which provides physical, emotional, and sometimes spiritual help to terminally ill persons and their families. With hospice support, a dying person may be able to remain at home. Many hospice programs are sponsored by home health agencies that use the same health professionals to provide home health care and hospice care.

Hospice care attempts to:

- decrease the pain and discomfort of the patient by controlling the symptoms of the illness.
- make life as full and meaningful as possible until death.
- provide support for the patient, the family, and the friends.

Hospice care is usually available 24 hours a day, seven days a week. When a physician certifies that a Medicare beneficiary is terminally ill, that beneficiary may choose to receive comprehensive hospice care provided by a certified home health agency or hospice program in lieu of the usual services available under Parts A and B of Medicare.

- **Meals-on-Wheels** provides hot, nutritious home-delivered meals once, and sometimes twice a day, five days a week, to persons who are unable to cook for themselves. There is usually a sliding fee for meals, determined by each individual's ability to pay.
- **Respite Care** offers support so family or friends can take a break from the demands of continual home care. When a family or friends care for a person in their home, they may need temporary replacement support when they are unable to provide the care that is needed, i.e., during a vacation, an emergency, or working hours. Respite care offers this support.

Respite may range from short term care provided for a few hours, 24 hours, to an extended number of days or weeks. It may include nursing care, chore services, and meals depending on the provider. A respite care staff person or volunteer may come to the home and stay with the person when family or friends must be away. Or a respite center may have an in-house facility where the individual can choose to stay while the family is away. The cost varies according to the amount of support needed. Respite is not yet widely available.

- **Transportation programs** provide transportation to needed services such as physician visits and grocery shopping for individuals who are unable to transport themselves. Transportation may be by volunteer drivers or by bus, taxi, or specially-equipped van service.

Information about these services can be obtained from home health agencies, public health departments, churches, day care centers, senior citizen centers, social service departments, Area Agencies on Aging, and civic clubs.

HOW CAN FAMILIES AND FRIENDS HELP?

There are many ways for relatives or friends to support sick and homebound patients, with or without the

help of a home health agency. This support can be both physical and emotional. A person often feels more comfortable with family help than with a stranger in the home; close relatives or friends can provide this feeling of intimacy and comfort.

Family members or friends can also reduce the costs that would otherwise be incurred by helping with the following tasks:

- personal hygiene (bathing, toilet)
- changing bed linens
- house cleaning
- preparing meals
- grocery shopping
- washing clothes
- helping the patient in and out of bed
- assisting with medications.

Family members or friends uncomfortable or afraid to care for a person's needs in the home might benefit from health training instruction available through local Red Cross chapters, home health agency nurses, or health department visiting nurses.

Families who are considering, or are providing, home care for a person and want more detailed information on what they can do, should consult one or more of the books listed as resources at the end of this Handbook. These books provide both clear direction on basic care needs that family members can provide, as well as explaining what broad needs and issues are involved in caring for someone at home. They can be very helpful to families who want to help.

HOW DOES HOME HEALTH CARE COMPARE WITH INSTITUTIONAL CARE?

A need for institutional care usually arises when a person has a "chronic" ailment, a condition of long duration that can recur frequently.

Institutionalization may be necessary when the condition is so severe or debilitating that the person is unable to care for himself or herself or friends and relatives are either not available or unable to help. A chronic illness, however, does not necessarily require institutional care.

For several years, the government has issued reports on the effectiveness of home health care. A study by the General Accounting Office* found that when expanded home health care services were made available to the chronically ill elderly, longevity and client-reported satisfaction were improved. These services, however, did not reduce nursing home or hospital use or total service costs. Home care can be less costly for an individual than institutional care, however. Some of these savings may be attributed to the support provided by a person's family and friends. Uncertainty over cost savings has resulted in a very cautious approach to the expansion of publicly supported home care benefits.

If problems occur with the selected home health agency, local consumer groups, such as the Better Business Bureau or local Consumer Affairs office, should be contacted. Also, if the agency is a member of a national group, the association should be notified. A listing of the national groups is included in the Resource section.

If a Medicare beneficiary disagrees with a decision on the amount Medicare will pay on a home health care claim or whether services received are covered by Medicare, the beneficiary may request a review of the claim by the Medicare carrier. If the beneficiary disagrees with the review decision, and the amount Medicare would pay is $100 or more including other claims within the past six months, the beneficiary can request a hearing by the carrier.

*U.S. General Accounting Office. Report to the Chairman of the Committee on Labor and Human Resources. United States Senate. "The Elderly Should Benefit from Expanded Home Health Care, But Increasing These Services Will Not Insure Cost Reductions," Washington, D.C., 1982.

EVALUATING THE QUALITY OF HOME HEALTH SERVICES

In some communities there may be only one home health care agency, but when several choices are available, the patient or family should try to make an objective evaluation of which agency is most suitable for the homebound person.

After home health care services begin, this evaluation should continue. The patient and family should discuss the care received and decide if it is adequately meeting the patient's health needs. The consumer should know that there are inconsistencies in the quality of care. There is evidence of lack of staff training, poor supervision, and examples of poor care and abuse from some home health agencies.

The checklists at the back of this Handbook can be used to compare the type of services offered by several different agencies. By answering the questions and filling in one column for each agency, it is easier to determine if an agency has met quality standards and can provide the services needed by the patient. Space is also provided for cost comparisons between the services offered by different agencies. The final section of Checklist B is to be used after service begins to assess satisfaction with the services provided.

HOW TO ARRANGE A HOMEBOUND PERSON'S ENVIRONMENT

There are many simple, inexpensive ways to make a home safer and more comfortable for a homebound person. Most of the equipment that may be needed to make these home adjustments can be bought at a hardware store; other adjustments can be made at no cost. Major drug stores and department stores have special catalogs for home care supplies and equipment.

- If a patient is confined to bed, make sure a TV, radio and telephone are accessible, as well as books and magazines, a reading lamp, call bell, water pitcher and glass, clock, and calendar.
- Avoid stairs. Use a first floor room even if it means converting another room into a bedroom. If steps can't be avoided, try to install a ramp.
- A colorful room with large windows and a nice view is pleasant for a bedridden patient.
- The bathroom should be on the same floor, close to the person's room.
- Grab-bars or hand-rails can be purchased and installed in hallways and in bathrooms next to the toilet and in the shower. Bars make walking and getting up and down easier and safer. (Cost @ $10-$35)
- Remove all elevated door sills or avoid them with a ramp.
- Shag carpets, slick floors and scatter rugs should be eliminated because of the danger of falls.
- Make sure lighting is bright and adequate in the person's room and hallways.
- In case of fire, prepare a plan of escape for the bedridden person.
- If a person is hard of hearing, install an amplifier on the phone and turn the phone buzzer on loud.
- Adhesive strips can be applied to the bathtub to prevent slipping. (Cost @ $5)

- A bench can be placed in the bathtub for easy and safe access. (Cost @ $18-$160 depending on the style and material.)
- Wrist-straps can be made for walkers and canes to prevent dropping them. Straps can be made of tape, cloth or rope.
- Enlarge handles of knives, forks and spoons to enable weak or arthritic patients to hold the utensils with less effort and more control. Foam rubber, velcro, cloth, garden hose, etc., can be used.

- Change door handles to a lever style rather than a knob to assist weak or arthritic patients. (Cost @ $15)
- Plastic mattress covers protect a bed if a person eats or bathes in bed or is incontinent. Add a mattress pad over the plastic for comfort and to avoid slipping. Since these pads must be changed immediately when soiled, several will be needed.

At more expense, the following equipment can be obtained to make a homebound person more comfortable. This equipment can be purchased or rented through a hospital, surgical supply store, or pharmacy. Depending upon a person's medical condition, Medicare and Medicaid may reimburse for some of these items.

- Buy or rent an electric or manual hospital bed to help the patient sit up and get in and out of bed. (Cost @ $1400 for a new electrical hospital bed; rental costs vary.)
- Purchase side-rails for a regular bed if a person needs help getting in and out of bed or something to hold when turning over in bed.
- A water bed, air mattress, or foam padding can be purchased for a person confined to bed to reduce the chance of bedsores. (Costs vary)
- A trapeze can be purchased and installed above a bed so the patient can grab it to move around in bed. (Cost $40-$300)
- An overbed table like those used in hospitals facilitates eating, reading, and writing in bed. (Cost $20-$175)
- An easy lift chair is a mechanical or electric chair whose seat lifts up to make getting in and out of a chair easier.
- A standard hospital type wheelchair costs $300-$800.
- Secondhand chairs may be available from the Red Cross or Salvation Army.
- A walker increases safety and ease in walking alone. (Cost $40-$65)

DEFINITIONS

AMBULATORY. The ability to walk around without assistance.

AMBULATORY WITH ASSISTANCE. The ability to walk around with the aid of a cane, crutch, brace, wheelchair, or walker.

BEDSORE (decubitus ulcer). A sore or ulcer caused by lack of blood circulating to some area of the body. This condition usually results from sitting or lying too long in one position.

CATHETER. A tube passed through the urethra into the bladder to drain urine.

CHORE SERVICES. Shopping, marketing, transportation, heavy cleaning, and similar services available alone or in combination with homemaker-home health aide service. Costs for these services are usually *not* reimbursed by Medicare. Some agencies provide chore services only, without home health care or nursing supervision.

CONTINENT. The ability to control the passage of feces and urine.

DECUBITUS CARE. The care of a bedsore. Treatment includes medication and dressing; a nurse can instruct the patient on proper bed positioning to prevent further irritation.

GRAB BARS. Railings placed on walls to steady oneself as a safety measure.

HOMEMAKER-HOME HEALTH AIDE SERVICES. Personal assistance and homemaking services provided in the home to sick or disabled persons who cannot perform basic tasks for themselves. Services provided include shopping, meal preparation, light housekeeping, assistance with personal care, administering oral medications under supervision, and reporting patient progress to the home health nurse.

MEDICARE CARRIER. Insurance company which processes Medicare claims in the beneficiary's state (or area).

PULSE. A measure of the rate and force of blood as it is pumped by the heart, which indicates the number of heart beats per minute.

REGISTERED NURSE (RN). A person who has successfully completed a minimum of two years of nursing education at an accredited school of nursing. Nurses must be licensed by the state in which they work. (Some graduate nurses can practice in certain states for a short time prior to passing a licensing exam.)

RESPIRATION. The act or process of breathing.

SELF-CARE. Bathing, dressing, toileting, and feeding oneself.

SPEECH-LANGUAGE PATHOLOGIST. A person who has a graduate degree and is certified by the American Speech-Language-Hearing Association. The speech-language pathologist can assess the patient's problem, design a treatment program, and provide therapy to help the patient regain or maintain speech or language skills.

SOCIAL WORKER. Usually an employee of a home health agency or a social service department who is available to help a person adjust to confinement at home. The social worker also counsels family members in caring for the patient. If community services or financial assistance are needed, the social worker can recommend sources of help.

VITAL SIGNS. Pulse, temperature and respiration.

WALKER. A lightweight frame held in front of a person to provide stability in walking. A walker is more stable than a cane.

CHECKLIST FOR SELECTING A HOME HEALTH AGENCY (A)

	Name of Agency				Name of Agency			
	Address				Address			
	Phone #				Phone #			
Services:	Yes	No	Cost Per Visit	Reimbursement (Type & Rate)	Yes	No	Cost Per Visit	Reimbursement (Type & Rate)
Nursing								
Physical Therapy								
Speech Therapy								
Occupational Therapy								
Homemaker & Personal Care								
Social Work								
Nutrition Therapy								
Dental Care								
Medical Supplies and Equipment								
Service Availability: Hours/day								
Days/week								
Staffing: (specify #) Supervisors								
RNs								
LPNs								
Homemaker-Home Health Aides: ▪ Hours of initial training								
▪ Required Hours of Continual In-service Education								
Staff Supervisor: ▪ Assumes responsibility for care given								
▪ Qualifications								
▪ Visits Patients								
▪ Frequency of Staff Contact								
▪ Available in Emergency								
▪ Provides Instruction to Homemaker-Home Health Aides								
Miscellaneous: Current Operating License								
Frequency of Physician Consultation								
Waiting Period for Service								
Translators (Specify Language)								
Geographic Areas Served								
Certification by Medicare and/or Medicaid								
Written Personnel Policies, Basic Benefits and Wage Scale for Each Position								

	Name of Agency Address Phone #				Name of Agency Address Phone #			
Miscellaneous: (continued)	Yes	No	Cost Per Visit	Reimbursement (Type & Rate)	Yes	No	Cost Per Visit	Reimbursement (Type & Rate)
Public List of Board of Directors or Community Advisory Committee								
Annual Report of Operations Available								
Written Statement of Who is Eligible for Service and Under What Conditions, Statement of Patient/ Client Rights, Problem solving mechanism								

CHECKLIST FOR EVALUATING A HOME HEALTH AGENCY SERVICE (B)	Name of Agency Address Phone #		Name of Agency Address Phone #	
Physician Supervision:	Yes	No	Yes	No
Patient Can Call				
Physician Visits Patient				
Staff Consultation Weekly or Bi-Weekly				
Staff Supervision: Patient Can Call				
Supervisor Visits Patient				
Staff Consultation Weekly				
Patient/Family Satisfaction: (to be completed after service begins) Comfortable with Staff				
Informed of Care Plan and Progress				
Observable Response to Treatment				
Questions/Concerns Answered				
Services Expected are Received				
Scheduled Visits Kept				
Needed Services Added				
Unneeded Services Terminated				
Periodic Reassessment of Care Plan				

Thirty-nine states license home health agencies. In addition, several national organizations accredit home care providers. Although accreditation is not a substitute for public regulation, it can serve as one of several indicators that a provider has attempted to meet some standards. Currently, accreditation is offered by the Joint Commission on Accreditation of Health Care Organizations, the National League for Nursing and the Hospice and Home Care Foundation.

RESOURCES

FREE PUBLICATIONS FROM AARP

Making Wise Decisions for Long Term Care, D12435, a guide to long term care services and financing.

Checklist of Concerns for Caregivers (D12895)
Offers caregivers a simple tool for evaluating their situation and determining how to best cope with their needs.

A Path for Caregivers (D12957)
A guide for individuals with caregiving identifying both national and local resources.

Nursing Home Life: A Guide for Residents and Families (D13063)
Offers information on selecting, entering and living in a nursing home. A consumer checklist is included.

Before You Buy: A Guide to Long Term Care Insurance (D12893)
Provides tips on evaluating the need for long term care insurance as well as on comparing policies.

How to order:
Single copies—send postcard noting titles and stock numbers to
AARP Fulfillment
1909 K Street, N.W.
Washington, D.C. 20049.
(Please allow 6-8 weeks for delivery)
Bulk orders—Send your request on your organization's letterhead to
AARP
Program Resources Department
1909 K Street, N.W.
Washington, D.C. 20049.

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Add $1.75 per order for postage and handling, and allow four to six weeks for delivery. Purchases may be charged to VISA or MasterCard accounts by including the account number and card's expiration date with the order.

Horne, Jo.
Caregiving: Helping an Aging Loved One, 1985
AARP Books
Washington, D.C.
Glenview, Il

A comprehensive and realistic look at the role of the caregiver, with practical advice and sound information on providing living arrangements, handling financial and legal matters, and getting help from others.

Other
Nassif, Janet Zhun, The Home Health Care Solution. A Complete Consumer Guide, New York, Harper and Row, 1985. A complete discussion of home care options, how to make choices and plan for future needs.

NATIONAL HOME CARE ASSOCIATIONS

American Federation of Home Health Agencies

1320 Fenwick Lane, Suite 500
Silver Spring, Maryland 20910

American Hospital Association
Division of Ambulatory and Home Care Services
840 North Lake Shore Drive
Chicago, Illinois 60611
(312) 280-6000

Community Health Accreditation Program
National League of Nursing

10 Columbus Circle
New York, New York 10019
(212) 582-1022

Home Health Services and Staffing Association

815 Connecticut Avenue, N.W., Suite 206
Washington, D.C. 20006
(202) 331-4437

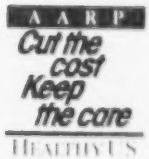
National Association of Home Care

519 C Street, N.E.
Washington, D.C. 20002
(202) 547-7424

Visiting Nurse Association

(Check your telephone directory for the nearest association).

Health Advocacy Services Program Department



"Healthy US" is the major national campaign of the American Association of Retired Persons to help reduce the skyrocketing health care costs that are weakening our health care system and our national economy. The campaign includes political and consumer action, and health promotion activities. To learn how you can help, write "Healthy US," AARP, 1909 K Street, N.W., Washington, D.C. 20049.

American Association
of Retired Persons
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Washington, D.C. 20049

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